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The Experience Of Caregiving And The Expressed Needs Of Children Of Elders

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THE EXPERIENCE OF CAREGIVING AND THE EXPRESSED NEEDS OF CHILDREN OF ELDERS

by

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Abstract

The purpose of this qualitative ethnography was to describe the experience of caregivers who resided with their elder dependent parents and to discover caregiver needs. The American Nurses' Association definition of nursing guided this inquiry. Five women between the ages of 35 and 73 who cared for and shared residence with their dependent elder parents were recruited by acquaintance or from a local home health agency to participate in the study. The researcher-developed Lewis Caregiver Expressed Need Interview Guide which consisted of five open-ended questions derived from a review of relevant literature was utilized to guide the interviews. As prescribed by Field and Morse's (1985) method of data analysis, interviews were transcribed verbatim and concepts and subconcepts were discovered in the data. The findings reflecting the experience of caregiving and a discovery of caregiver needs assisted the researcher in identifying three concepts: Needs, Motivation, and Helpers/Hindrances; and six subconcepts: Quiescence, Emancipation, Love for Parent, Avoiding Institutionalization, Family, and Formal Support. These concepts and subconcepts contributed to uncovering the Model of Kinkeeper for Caregivers. This

model has consideration as a Level I theory. This model offers to nursing an explanation of the behaviors of caregivers and provides an improved understanding of the process of caregiving. Further research and development of the model to a Level I theory is recommended as well as implementation of family-as-client interventions in undergraduate nursing curricula.

Dedicated in Loving Memory

of

Grandad

Theodore Roosevelt Beersdorf

October 9, 1906 - October 1, 1993

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Chapter I

The Research Problem

Establishment of the Problem

The number and proportion of older persons in the United States population have been increasing steadily since 1900 (Beigel, 1984). People aged 65 or over have increased from 3 million (4% of the population) in 1900 to 25 million (11% of the population) in 1985 (Brody, 1985). Projections have been that they will number 31.8 million (12.2% of the population) by 2000 and 51 million (17.2%) by 2025 (Brody, 1985). Equally significant to these figures has been the changing age structure of the aging population. Between now and the year 2000, those between the ages of 65 and 74 will have increased by 23% and those 75 to 84 by 57%, and the 85 and older group will have doubled in size (Brody, 1985).

One of the consequences of an increase in life expectancy and the growth in the number and percentage of the elder population has been a shift toward multigenerational families. Specifically, there has been a demand upon family members to provide care for these elders at home (Franks & Stephens, 1992). Thus, families

have been found to be steadfast as the principal caregivers of older people (Brody, 1985).

However, according to Johnson (1983), caregiving rarely occurred as a unit of people whose members cooperate and interchange the caregiving role. Instead, one individual, usually female, provided a large portion of the care to a seriously impaired relative. Therefore, the caregiver was subject to greater stress and risk of becoming overburdened.

Caregiving research has developed along two major themes. The first focused on the description of the caregiving process with major emphasis on the effects of caregiving on the caregiver. As the central feature of these studies, "burden" was frequently treated as the primary outcome measure, while at other times it was used as a predictor of other outcomes, such as depression of the caregiver in institutionalization of the elder (Beigel, 1990). The second and least researched theme focused on the interventions that addressed caregiver and patient needs.

There has been a significant amount of research relating to the issue of family burden--the strains felt by the caregiver of the elder (Brody, 1985). The most significant problems for caregivers identified by researchers were coping with physical and mental illness and increased needs of the elder (Poulshock & Deimling, 1984; Robinson, 1983). Burden scales have been developed

(Zarit, Reever, & Bach-Peterson, 1980), and burden has been correlated with a variety of caregiver and care-recipient demographic and socioeconomic characteristics (Brody, 1983). Finally, caregivers emerged as an at-risk population in a study investigating perceptions of familial caregivers of elder adults (Sayles-Cross, 1993).

Fewer studies focused on the second theme in caregiving research, the needs of and interventions for caregivers. In 1991, Smith, Smith, and Toseland identified goals of family caregivers in counseling sessions to evaluate impact of supportive psychoeducational interventions for this client population. Many of the family related problems were focused on relinquishing control of the caregiving situation. Thus, use of formal and informal support was often hindered by the fear of abdicating responsibility and control to others. Financial resources and needs of families providing in-home care for relatives with disabilities were studied by Arnold and Case (1993). These families reported their most urgent needs to be financial assistance, medical care, and job placement services.

In summation, although these clinical studies have enhanced understanding of the problems faced by family caregivers, the primary objective of the majority of studies has been to describe the caregiving experience.

Few studies have been conducted which focused on caregiver needs and even fewer studies have been found which utilize a qualitative approach for these lived experiences. The subjective experience of caregivers may be better facilitated by qualitative research methods as well as provide data significant to nursing for intervention and provision of caregiver needs.

Significance to Nursing

The trends of the aging population were considered significant to nursing because this population was found to be more likely to have health problems, require assistance in meeting the needs of daily living, live alone, and be at greater risk for institutionalization (Franks & Stephens, 1992). Furthermore, the demand of this growing population cannot be met by the present formal social system (Brody, 1985).

Current trends toward earlier discharge from hospitals and an expected increase in in-home care may result in more adult children becoming involved in caring for physically dependent parents. An awareness of the requirements evoked by a care-taking relationship may then anticipate needs that may otherwise increase the burden of caregiving. Involvement by health and social professionals is required if life satisfactions are to endure for both adult child and parent (Robinson & Thurnher, 1979).

It will be necessary for nursing to empower the growing number of familial caregivers and advocate responsible programs needed to strengthen and supplement family efforts. In order to accomplish this, further observance of caregiver research with regard to needs and interventions must be instituted. Thus, the purpose of this qualitative ethnographic study was to further explore and validate the needs of caregivers of elder parents.

Theoretical Framework

In congruence with the American Nurses' Association's definition of nursing, "the diagnosis and treatment of human responses to actual or potential health problems" (1980, p. 9), this study was guided by the principle that individuals and families, well or ill, require education in matters of health, anticipatory guidance, and therapeutic counseling to resolve problems or manage health problems. In essence, the American Nurses' Association has taken the position that as a result of environmental and hereditary factors, each human being possesses various strengths and limitations. Since these strengths and limitations have been determined to place individuals on the health continuum, they also determine the person's biological and behavior integrity.

Caregivers likewise possess strengths and limitations. Therefore, it is necessary that these strengths and limitations be identified so nursing

knowledge in the form of theory may guide nursing practice for the purpose of caregiver well-being on the health continuum. It was upon this premise that this study was conceived, and the intent of this research was to describe the experience of caregiving and discover caregiver needs.

Statement of the Problem

In this study, the problem explored was twofold: to describe the experience of caring for an elder parent and to discover the needs of caregivers.

Definition of Terms

For the purpose of this research, the following terms were defined:

1. Caregiver: The adult who shared residence with the elder parent or parents for a minimum of one year and assisted in at least one of the following: personal care, shopping, or preparing meals.

2. Elder parent: The adults, age 65 years or older, who required assistance in at least one of the following: personal care, shopping, and preparing meals.

Chapter II

Review of the Literature

Caregiving research has been based on two major themes: a description of the caregiving experience with emphasis on the effects of caregiving on the caregiver and the needs of caregivers. A review of the literature revealed a majority of studies that have proposed to describe the caregiving experience, especially concerning burden and role conflict. The few attempts by researchers to discover caregiver needs used a quantitative design.

The concepts of role conflict, role fatigue, and role constriction were identified in a study by Goldstein, Regnery, and Wellin (1981). Interviews and observations in the homes of a randomized sample of 60 long-term patients confirmed that the caregiver role entailed both rewards and costs--the latter involving role conflict, but more often role fatigue. The extent of these concepts varied for caregivers, and the following variables had a significant impact: the patient's level of disability and dependence, the caregiver's own health and functional mobility, the presence or absence of other assistance, and the caregiver's other roles and responsibilities. Goldstein et al. concluded that confinement of the

caregiver in the home and restricted activities were the most severe problems and led to role fatigue.

Furthermore, the researcher concluded that for home maintenance of the chronically ill to be effective, it was necessary to meet the needs of the caretaker as well as those of the patient. Although Goldstein et al. (1981) did not recommend research to discover those needs, they acknowledged the deficiency of solutions.

According to Franks and Stephens (1992), researchers had not examined the caregiving role in the context of caregivers' other roles. The purpose of their study was to examine the caregiving experiences of middle-generation women in the context of their experiences in other family roles, specifically those of mother and wife. It was hypothesized that stressful experiences in the roles of mother and wife would contribute to the explanation of well-being beyond that contributed by stressful experiences in the caregiver role.

Caregiver was defined as a married female, living with her husband, and at least one child under age of 21 living in the home, who had to assist her relative with at least one of three activities of daily living (personal care, shopping, or preparing meals) or she had to be responsible for supervisory care of a relative with dementia.

Questionnaires were mailed to eligible respondents. The questionnaire was divided into three parts: role

stress, role adequacy, and rating of physical health. Hierarchical multiple regression analyses were used to test the hypothesis that stress in the mother and wife roles accounted for significant portions of variance in well-being beyond that accounted for by stress in the caregiver role.

The sample consisted of 106 caregivers. Of these, 71% were daughters and 20% were daughters-in-law. The mean number of years that the subjects were married was 19, while the mean age of the youngest child living at home was 12. Caregivers had been providing care to the care-recipient for an average of 3.5 years, and the average age of recipients was 76.2 years.

Findings from this study generally supported the hypothesis. The most frequently endorsed stressor in the caregiver role was heavy demands or responsibility for the children. Also included among the top ranked stressors were arguments or conflicts between the respondent and her children. Although stressors in all three roles of wife, mother, and caregiver were related to reduced feelings of adequacy in these roles, only in the caregiver and wife roles were feelings of adequacy consistently related to well-being. The feelings of adequacy in the caregiver and wife roles were less directly related to current stressors (those occurring in the past 2 months) than were reduced feelings of adequacy in the mother role.

Franks and Stephens (1992) determined that stress in the mother role contributed unique variance beyond that contributed by stress in the caregiver role. For physical health, both mother and wife role stress were significant predictors, whereas caregiver role stress was not. Thus, different patterns of role stress were important in explaining domains of well-being.

The findings of this study underscore the value of examining caregiving stress in the context of other role stressors in caregivers' lives. For this reason, this researcher designed the Lewis Caregiver Expressed Need Interview Guide (see Appendix A) with other potential roles considered, specifically occupation, rather than wife and mother. Furthermore, this researcher defined caregiver in a manner comparable to the definition of the same term originated by Franks and Stephens (1992).

In an effort to assess caregiver well-being rather than burden, George and Gwyther (1986) researched four generic categories of well-being measure: physical health, mental health, social participation, and financial resources. Also, the relationship between living arrangements (whether the patient lived with the caregiver, in a nursing home, or other living arrangement) and the four indicators of well-being was studied.

Survey instruments were mailed to participants of a local family support system. Inclusion in the sample

required that the caregiver be providing some level of care to a memory-impaired adult. The sampling frame produced a heterogeneous, but not random, sample from a geographically large area. Levels of well-being in the caregiver sample were compared with available population norms to determine the degree to which caregiving led to decrements in well-being relative to random community samples. Of the over 500 families who participated, 32% of the primary caregivers were adult children.

The findings revealed that regarding physical health caregivers were similar to other populations. There was no evidence that the caregivers used more medical services or rated their health worse than random community samples. The mental health indicators, in contrast, exhibited large discrepancies between the caregiver and comparison samples. Caregivers averaged nearly three times as many stress symptoms as the comparison sample. Also, caregivers' levels of life satisfaction were considerably lower than those reported in other samples. Moreover, a substantially higher proportion of caregivers (28%) reported using more psychotropic drugs than the comparison sample (19%). Caregivers reported substantially lower levels of participation than the comparison sample for all indicators of social activities except church attendance. The sample of caregivers was more financially secure than

the comparison sample in terms of household income and perceived economic status.

Regarding living arrangements, and of significance to this study, George and Gwyther (1986) concluded that caregivers who resided with their parents were most likely to use psychotropic drugs, report the highest stress symptoms, and report lowest levels of affect and life satisfaction. Additionally, caregivers who lived with their patients report significantly lower household incomes than the two subgroups (patient living in a nursing home or other living arrangement). Furthermore, these caregivers reported the lowest levels of participation in and satisfaction with their social participation.

Robinson and Thurnher (1979) acknowledged that both ill health and the death of one parent and subsequent concern for the emotional, physical, and financial dependencies of the surviving parent were conditions which increased assistance by children. Using both quantitative and qualitative methods, Robinson and Thurnher focused on the perspective of the adult child caregiver and examined perceptions and attitudes toward the parent, the ways children met their parents' needs, and the stresses generated by the caretaking relationship.

The study involved 49 respondents who had living parents and consisted of men and women who were expected

to undergo the transition to the empty nest or the transition to retirement (or retirement of spouse). The respondents were studied intensively at baseline (with open-ended but structured questions, checklists, and rating scales) and were given abbreviated follow-up interviews 18 months and 5 years later.

The impact of the aging parents on the respondents' lives and goals had not been anticipated and, hence, examination was based on largely spontaneous narrative data and was essentially qualitative. Twelve percent of respondents were caregivers sharing residence with elder parents.

Gratifying relationships with parents seemed to depend largely on the relative independence of the parent and the values and cherished lifestyle of the child. Negative appraisals were most likely to occur in instances where caretaking functions were reported as confining and stressful. For these respondents, responsibilities for the care of the aged parent were perceived to occur at an inopportune time. With few exceptions, constraints in caring for a parent were experienced as severe, particularly for women (Robinson & Thurnher, 1979).

Consistent with other studies, stress resulted when the caretaking relationship was experienced as confining. Confinement was less clearly linked to the physical or mental status of the parent than it was to infringements

on the lifestyle of the adult child. As the child became more involved in performing services for the parent, the situation became more problematic.

In 1983, Robinson reviewed the above study systematically to identify the most common stressor in caring for an elder parent. Ten stressors were identified and became the basis for a new study that aimed to select and empirically validate a series of questions for use as an instrument for detecting caregiver strain. The 10 stressors were inconvenience, confinement, family adjustments, changes in personal plans, competing demands on time, emotional adjustments, upsetting behavior, the parent seeming to be a different person, work adjustments, and feelings of being completely overwhelmed. Three more stressors were added after relevant literature review: sleep disturbances, physical strain, and financial strain.

In the analysis of the Caregiver Strain Index (CSI), there were no significant differences in scores for men and women, nor did the relationship (spouse, child, nonfamily member) to the patient reveal significance. Furthermore, there were no significant differences in CSI scores between caregivers who lived with the patient and those who lived elsewhere.

In conclusion, Robinson and Thurnher (1979) failed to support the findings of the Caregiver Strain Index (Robinson, 1983). The caregivers of patients with severe

impairments reported quantitatively and qualitatively different strain, and the value of the CSI as a screening instrument requires further research as recommended by Robinson (1983).

Of the few studies found to address caregiver goals and needs rather than describing the caregiver process was a study by Smith, Smith, and Toseland (1991). According to these researchers, until the goals of family caregivers were clearly formulated and understood, practitioners would focus on intervention techniques that are inappropriate for this target group. This study was an in-depth analysis of the pressing problems that family caregivers elected to address in eight weekly one-hour individual counseling sessions. Key terms defined were psychoeducational programs, client goals, and adult daughters.

Participation was limited to adult women who were primary caregivers to a frail elder parent or parent-in-law. Recruitment was elicited through an extensive media campaign. Applicants were screened and chronic disabilities of the parent were assessed by self-report. Applicants rated their caregiving stress on a 5-point Likert-type scale, and only those with a score of 3 or more were included in the study. The sample included 51 participants selected using this process. The caregivers' average age was 50.2 years, 67% were married; 65% were

employed, 98% were white, and the average length of caregiving was 5 years.

Major categories of problems were improving coping skills, family issues, responding to elder's care needs, quality of relationship with elder, eliciting formal and informal support, guilt and feelings of inadequacy, and long-term planning. Although the findings presented a wide array of goals, it was noteworthy that many of the specific problems identified were the clients' underlying concern about sharing caregiving responsibilities while maintaining control over the caregiving situation.

The content analysis of clients' pressing problems indicated a number of important areas that should be addressed in psychoeducational programs for family caregivers. These include working on improving coping skills, involving other family members in counseling, helping caregivers to better understand and respond to the care receiver's psychosocial needs, encouraging caregivers to use formal and informal resources, encouraging caregivers to ventilate distressful feelings, counseling caregiver regarding possible residential placement, and attempting to improve the quality of the caregiver-care receiver relationship.

Smith et al. (1991) recommended the synthesis of a flexible and personalized counseling model which considers the unique needs of individual caregivers. Smith et al.

anticipated that further knowledge regarding caregiver needs was required for the establishment of such a model, thus validating the purpose of this research.

Although the study by Arnold and Case (1993) included care recipients of all disabilities (predominantly mental retardation and speech impairment), it was still applicable to this research. The study's purpose was to explore in detail the financial resources and needs and perceived coping abilities of families providing in-home care, which were issues pertinent to the current study in that it sought to discover needs for a population of caregivers that resided with the care-recipient. Furthermore, participants of the current study had similar financial resources from the sample represented by Arnold and Case (1993).

A seven-page questionnaire revealed the financial means of support for the disabled as well as for the caregiver. Combined earnings of the primary caregiver and the disabled showed that families who provided in-home care operated on extremely limited means. Twenty-one percent of total household incomes were under $5,000. Twenty-eight percent had annual incomes between $5,000 and $10,000. Twenty-one percent of total family income was between $10,000 and $15,000. Most of the families represented the working poor of the country, with gross annual incomes less than $20,000. Many of the families

utilized federal support, such as Social Security insurance and Social Security disability income, to supplement their income from regular employment.

Arnold and Case (1993) determined that the most urgent needs expressed by the families were for financial assistance (26%), medical care (7%), and job placement (6%). Dental care, respite care, transportation, special equipment and supplies, and speech therapy were each listed as most urgent by 4% of the families.

In conclusion, a review of literature with respect to caregiving revealed two themes: those studies that pertained to the effects of caregiving on the caregiver and those which addressed caregiver needs. Earlier research first acknowledged the role of caregiving as confining and that the needs of the caregiver as well as the chronically ill were important. Furthermore, a study recommended that caregiver stress be examined in the context of multiple roles--finding quantitative significance in stress for female caregivers. George and Gwyther (1986) recognized in-home carers to be at higher risk for mental illness and social isolation and again conceded that confinement was a common problem.

Also, the review of literature revealed that an attempt at placing empirical measures on caregiver stress was unable to support the paradigm of caregiving knowledge. Finally, the review lacked information

regarding caregiver need and intervention. Of all of the studies found, regardless of purpose, few studies were qualitative in method. Therefore, the subjective experience of caregivers captured by qualitative methods, combined with the broad research addressing the caregiver experience, would attempt to fill the void in present knowledge of caregiver needs.

Chapter III

The Method

Ethnography is a generalized approach to developing concepts to understand human behavior from an emic point of view (Field & Morse, 1985). According to Leininger (1985), an "emic" focus referred to the local or indigenous interpretation of behavior versus the "etic" meaning a universal explanation. Analyzing data as they come from the informants' viewpoint is essential for qualitative research. Such information is critical to enable nurses to better understand and provide care to caregivers.

Design of the Study

A qualitative ethnographic study was undertaken to describe the experience of caregiving and discover caregiver needs. An ethnographic approach to the study of nursing was useful in that it allowed the observer to view nursing in the context in which it occurs. An ethnography is a means of gaining access to the health beliefs and practices of a culture (Field & Morse, 1985). Therefore, an ethnographic approach was appropriate for this study in which interviews of caregivers in their homes were

utilized to describe the experience of caregiving and discover caregiver needs.

Setting, Population, and Sample

The setting of this study was the Gulf Coast area of Mississippi. Within this area was a large home health agency which provided care to homebound elders. The population was all adults who care for elder parents in the home within this region and were participants in home health care services. The criteria for selection required that the care-recipient, or elder parent, must be age 65 years or older and reside with the caregiver. Caregiving for the elder parent must have included assistance with personal care, shopping, or preparing meals and have occurred for at least one year.

A convenience sample of 5 caregivers who met the criteria and who were willing to participate was recruited. Four informants were recruited from a local home health care agency, and due to lack of available caregivers, one informant was recruited by acquaintance of the researcher.

Method of Data Collection

The method of data collection for this ethnographic study was audiotaped interviews. The subjects were given written invitations to participate in the study (see Appendix B) by the home health agency staff. The subjects were assured of confidentiality, anonymity, and the option

to withdraw at any time. Prior permission for study implementation was obtained from the Committee on Use of Human Subjects in Experimentation of Mississippi University for Women (see Appendix C) and South Mississippi Home Health Agency (see Appendix D).

Potential participants of the home health agency then contacted the researcher by telephone. At the convenience of the respondent, face-to-face interviews were conducted in the home of the caregiver. Prior to the onset of the interview and after the caregiver verbalized understanding, written acknowledgement of consent by signature on the Participant Agreement form was obtained (see Appendix E).

Instrumentation. To minimize the "dross rate," or amount of irrelevant information in an interview (Field & Morse, 1985), five open-ended questions, prepared as the Lewis Caregiver Expressed Needs Interview Guide, were utilized to focus the interview. The questions were devised from factors elicited from a review of relevant literature. Interviews were open-ended, allowing the researcher to explore and clarify new information with the informant. Therefore, as the process of exploration developed, the interview was directed by the informant's responses into areas previously unanticipated by the researcher.

Methods of Data Analysis

Descriptive statistics were used to describe the sample from the demographic data on the Lewis Caregiver Expressed Need Interview Guide. The method of data analysis for the taped interviews was that of Field and Morse (1985). Once data collection was complete, the interviews were transcribed verbatim by a professional transcriptionist, who was instructed that the material was not to be edited in any manner. Pauses were denoted in the transcript with dashes, while series of dots indicate gaps or prolonged pauses. All exclamations, including laughter and expletives, were to be included. Generous margins in the transcribed interviews allowed for the researcher's notes and coding. A modification of the Field and Morse method for analysis incorporated multiple transcripts of each interview photocopied in different color paper for visual simplicity. Once transcriptions were complete, each interview tape was destroyed as per the caregiver's request.

The researcher read and reread the data five times. As recommended by Field and Morse (1985), transcripts were coded for persistent words, phrases, or themes and noted in the margins. A manual data filing system was used by cutting the transcription sentences and phrases and sorting by category or phenomena. Because segments of data fit into two or more categories on preliminary

analysis, several copies of the data were utilized. Finally, as categories were collected, the researcher developed preliminary concepts and formulated tentative propositions about the concepts. Analysis of the concepts continued until all segments of data existed exclusively in one category.

For verification of analysis, all transcribed interviews were given to another researcher grounded in qualitative data analysis using Field and Morse. First, the primary researcher completed the analysis until segments of data were exclusive in one category. Then uncoded transcriptions of each interview were given to the collaborating researcher, and the primary researcher's findings were explored to determine agreement or disagreement with interpretation of the data. Findings of the two researchers were almost identical, and where discrepancy existed the primary researcher decision was respected.

A second contact with participants took place during data analysis as concepts emerged. The purpose of these encounters was to clarify findings with persons who were acquainted with caregiving which supported validity and decreased bias.

Chapter IV

The Findings

The purpose of this ethnographic study was to describe the experience of caring for an elder parent and to discover needs of caregivers. A qualitative ethnographic approach was utilized to explore the experience of caregiving from an emic point of view.

Description of the Sample

Five caregivers were enlisted in this study. Four of the respondents were recruited from a local home health care agency, and the fifth respondent was a willing acquaintance of the researcher. All respondents were female with ages from 35 to 73 years. Three of the caregivers were employed, one retired, and another unemployed. The number of years that caregiving took place ranged from 18 months to 13 years. Of the elder parents receiving care, 4 were fathers and 2 were mothers, with one caregiver caring for both parents at home. The ages of the elder parents ranged from 67 to 93 years old. All of the respondents were of middle-class Caucasian families.

Results of Data Analysis

A preliminary analysis of the data divided segments of data into the following initial concepts: Confinement, Respite Care, Exasperation, Love for Parent, Motivation for Caregiving, Home Health, Family, and Others who Help. Upon further analysis and until all segments of data existed exclusively in one category, the following concepts were established to describe the experience of caregivers and their needs. The impact of caregiving on the caregiver could best be described in terms of three concepts: Needs, Motivation, and Helpers/Hindrances. These elements contribute to the initiation of the model of "kinkeeping" for caregivers (see Figure 1).

Needs

Needs was defined as an element necessary for caregiver and elder parent well-being while facilitating mutual residence of caregiver and elder. The respondents clearly articulated two needs within the data: Quiescence and Emancipation.

Quiescence. Quiescence was defined as the temporary relief of the caregiver burden by a person or agency for the purpose of caregiver rest. A 43-year-old mother of two explained, "I would love just to be able to have some time off sometime." A 45-year-old daughter caring for both parents stated:

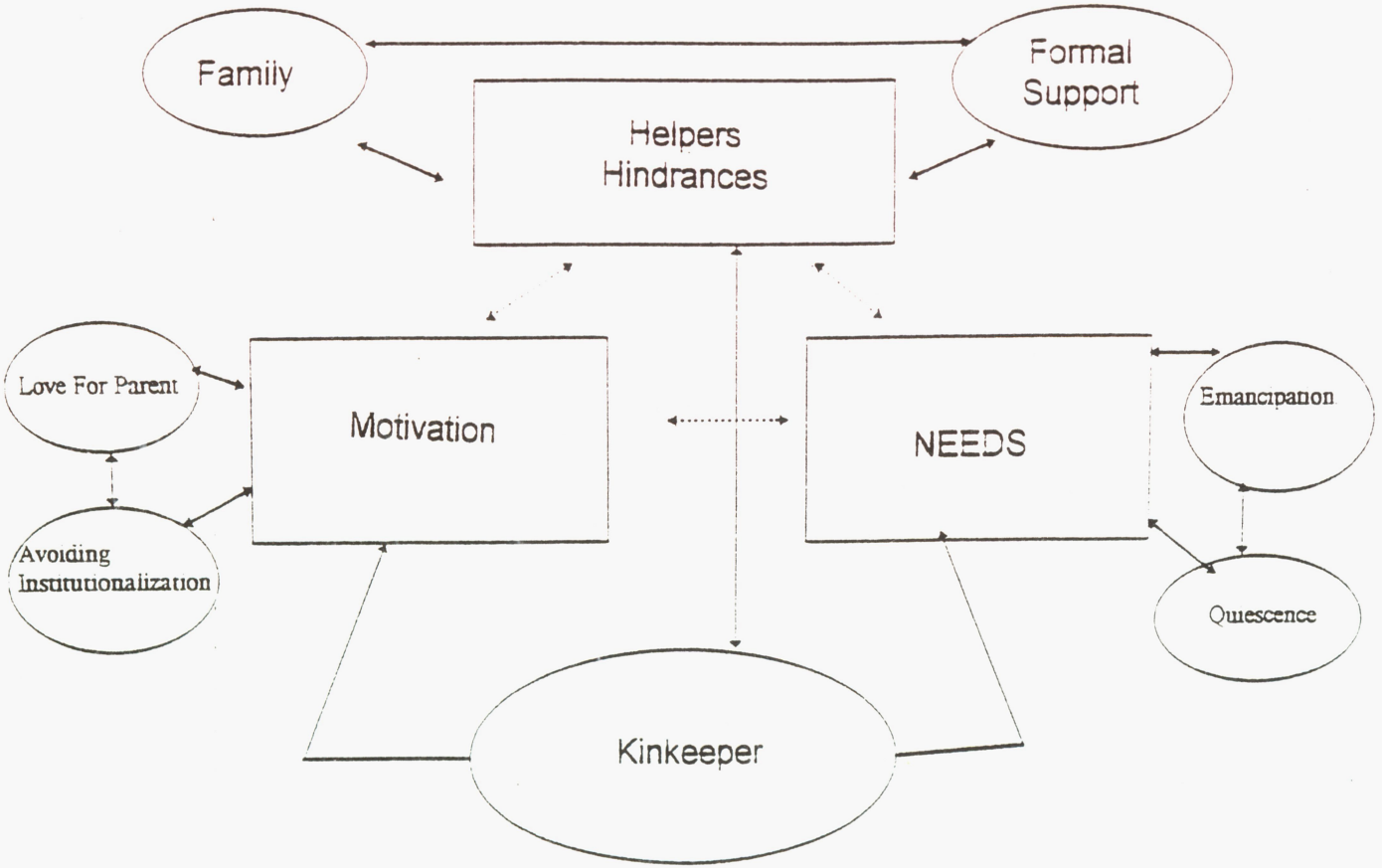

Figure 1. Model of kinkeeping for caregivers of elder parents.

> You know, it is very hard to find someone who will come in and live with somebody. And then, they (parents) can't afford it and I can't afford what it cost for full-time care for them, and the only way they could ever move back to their home is if I move back with them. And then, that's not really a good thing for my marriage.

The same caregiver later said:

> So, if I knew that there was another source available to come in and stay a few hours and let me out that would help. I can hang on if I can get a little bit of a break.

Another caregiver expressed the same idea:

> If I had to have a sitter, we'd make do somehow --but if I <u>wanted</u> a sitter--wanted to take off a few days--if I needed a break, he seemed to be doing fine, everyone that needed to be on call was on call in case of an emergency, but I just needed someone, and he needed someone to come in with him--see that he took medications, that he ate, and be company to him--that is all I would require. I really--I could do all the work. But there's not a service. There is not a business that does this. And there are some individuals that are called "sitters" if you can find one that's dependable.

A 73-year-old retired nurse caring for her 93-year-old father stated, "If there was just some kind of babysitter organization that you could call on and say I need to go away for 2 or 4 hours or something like that."

A 35-year-old caregiver described having no relief to be the "worst part" of caregiving:

> You have friends, you have good neighbors, and in an emergency you don't mind calling on them, but just to say "Hey, I need a break today"--you

> just don't do that. You feel like you are abusing their friendship.

The same caregiver later went on to say:

> If there was a service that you could call, and you knew you could call them on any day of the week at any hour of the day or night and you could have somebody there in just a little while, would be great.

Throughout the interviews, caregivers expressed the need for a person or "business" that was not only available, but qualified. For instance, one caregiver stated, ". . . they need some training before they can go into a home with a patient that is bedridden." Another caregiver reported, "I'm not afraid of help--I just want to be sure they are qualified."

Furthermore, the person or agency needed to be affordable. The 73-year-old retired nurse caring for her bedridden father stated, "I have tried the babysitters that are available. None of them have any professional background at all. I couldn't depend on them and they are wildly expensive and they won't take anything under eight hours."

Emancipation. Emancipation was defined as the relief of the caregiver from psychological and/or physical confinement of the duties of caregiving. One caregiver declared, ". . . but you can't just--like--you know--most

people do--just up and leave when you want to. But you gotta make first sure somebody is around home, you know."

The 73-year-old retired nurse affirmed, "It is very confining. I can't leave my dad for a minute unless he is being cared for." This caregiver's confinement also impacted her own health:

> I should walk and I should swim, but I have had to give up those two things because it takes up too much time away from him. . . I run and have my blood work done on the day that it is ordered and I come right back home. That is the only time that I go away from him at all. I do miss going to church. I do miss my swimming which I did at the "Y." I do miss my long walks which I should do because I am a diabetic and I should take a lot of exercise but I do have a few little exercises that I do at home.

She further affirmed, "I've had to give up my quilt club, home economist club--I talk to people or write to people. They respond to me by phone usually."

A third respondent commented:

> It finally became a little bit more difficult because, you know, I didn't have the freedom to come and go--you know, I had to make sure that she was alright and that, you know, if I wasn't going to be here that someone was around to check on her.

One more caregiver communicated, "He is so afraid of being left alone so I don't leave him for a minute unless there is somebody right in the room with him."

Finally, a caregiver summarized caregiving this way:

> The only thing I can tell you about caregiving is that it is very confining--very, very, very confining, especially if the patient is accepting you for all his support, whether it be his medical needs or his psychological needs, you have to be there and I have nobody to depend on except for the occasional visit from somebody.

Motivation

Motivation was defined as an emotion or will that persuades the caregiver to continued caregiving in spite of adversity. The caregiver's responses to the researcher's question "What gets you through?" can be described in two subconcepts: Love for Parent and Avoiding Institutionalization.

Love for Parent. Love for Parent was defined as the caregiver's affection for the parent that elicited motivation for caregiving. Some of the responses from different caregivers included, "I want to help my daddy. Because I love my daddy, and I want to help him" and "It's my daddy and I love my daddy. That's just it--I love my daddy." Another response was this:

> Knowing that Momma and Daddy love me and even though there are days they may not act like they appreciate what I'm doing, they do. They don't want it to be the way it is--but that will get you through it.

Another caregiver responded:

> I have had him for 93 years. I have always been his child. He calls me his angel of mercy--my guardian angel--my angel of mercy, and he has

> always said it ever since he came to live with me in '81. We have done things together and had good times together.

Finally, a caregiver summarized her motivation for caregiving this way: ". . . he is my daddy and I want to take care of him and it is no effort for me to do anything for him and he appreciates it."

Avoiding Institutionalization. Avoiding Institutionalization was defined as the caregiver's reservation to institutionalize the elder parent which persuaded the caregiver's motivation for caregiving. This concept was elicited in such comments by different caregivers, such as "I don't regret it, you know he is my daddy and to keep him from a nursing home, I'd do anything" as well as, "I don't want him to go to a nursing home. I have heard him so many times when he was in better health and more coherent that he never wanted to be put in a nursing home."

A final comment reflecting this concept was

> I thought as long as they could be with family and we could do things and they could have the freedom to, as I said, to grab a peach and run out on the porch--things like that--that they might live longer and have a little bit better quality while they are here.

Helpers/Hindrances

The final concept, Helpers/Hindrances, was defined as those people who impacted the experience of caregiving in

either a negative or positive manner. These include Formal Support and Family.

Formal support. The influence of formal support systems, specifically home health, as a positive agent in the caregiving experience was indicated by the caregivers as noted in the following comment: "I don't think he would get to stay at home if it wasn't for home health right now" as well as the comment:

> I can't get him out by myself and that's another reason why the home health is such an important part right now because many times we would have had to take him to the doctor where the home health has been able to call the doctor and get order from him.

One caregiver who was confined to her home due to caregiving said, "I can always depend on an hour and a half of free time when the home health nurse comes in. She insists that I sit down." Another caregiver caring for her mother who had cancer stated:

> The main thing is the home health care. That has been a help--because they are here at least once a week, and they draw her blood and so, that saves us a trip from having to go to Mobile because her doctors are at South Alabama. That helps a lot.

Family. Family existed as both a positive and negative agent for explaining the experience of caregiving. More often, family members precipitated negative consequences for the caregiver than the following

more positive insights made by two caregivers: In response to the researcher's question, "What about needs for your support?" the caregiver responded, "Friends and family. Especially family. My brother and sister are here a lot and help out. We take turns."

Likewise, a second caregiver, referring to her teenage daughter's relationship with her grandfather, stated:

> I mean, she loves this man, and she'll wake him up and make sure everything is okay. Then she will fix him a biscuit, or toast or something. She'll come home and take him to McDonald's. She is the one that takes him to the doctor. She does all the little stuff like that for me.

However, the majority of caregiver comments regarding family were negative, implying that male family members, including brothers, husbands, and nephews, presume the role of caregiving is for the female and resist assistance to the primary caregiver. A caregiver referred to her brother:

> He never comes over to get Daddy and just take him over to their house for the day. Or to spend the night or they don't call. But I know they love Daddy, and when there is an emergency, when he is sick, they are there . . . but I don't feel like I should have to call and ask--I feel like they should be checking and say "what can we do?"

She further commented:

> I don't think it's asking too much for my brother to live here--like one Saturday a month, or like on a Friday afternoon come over and get Daddy and let him stay that Friday and Saturday night and bring him home Sunday. Just that one time a month. So it would where I could just do something and not have to worry about it . . . I even had one of my brothers tell me "There is no way I could do that for Daddy," and he says he is not being ugly about it . . . changing those diapers and all that, he said he could not do that. And I want to say, "Well, do you think it is pleasant for me?" I don't regret it, but I still think he's [brother] got the better end of the deal.

Likewise, another caregiver speaking of her brother commented:

> I said, "I need somebody to keep Pappy" and he went, "I will not do it." I mean it was that fast and I thought, "for one week you will not keep your father" and he said, "Nope." He has a maid, he is the only person--he lives alone, his boys and ex-wife are up in Pennsylvania, but he wouldn't keep him. He said, "You find somebody and you pay them--we will pay them whatever they want."

A third caregiver referring to bathing her father said of her husband, "Joe don't feel comfortable doing it, and I hate to ask him." She later reported about her brother saying, "They just want to put him in a nursing home and check on him three or four times a day."

Furthermore, a caregiver speaking of her husband said,

> If something happened to me, my husband could not handle them by himself. He is very good. He helps all that he can, but he does work, and he is man and men are . . . they deal with things differently. I know he loves them, he just could not take care of them the way I can.

Finally, a caregiver referring to her nephew reported this incident when her father became very ill and vomited:

> I called Kevin to come help me. He said, "Aunt Linda, I can't. I can't. I'm sorry, I can't." I said, "Kevin, you have got to. You have got to!" [He said] "I can't--you know I can't." [Caregiver said] "I don't like it either Kevin, but this is your Grandpa, and have got to do it. Now you just forget what you are doing and help me." I thought he was about to die.

Summary

The experience of adult child caregiving and caregiver needs involved a process designated as Kinkeeping. Within this study the process of kinkeeping was expanded to embrace three concepts: Needs, Motivation, and Helpers/Hindrances. The role of caregiver was perceived by the informants to be thrust upon them by their male relatives who subsequently offered little aid. As a result, the caregivers experienced substantial burden and confinement. The caregiver needs that emerged included Quiescence and Emancipation. Nevertheless, these daughters were inspired by love for their parents and the wish to keep them home.

Chapter V

The Outcomes

In this chapter the researcher summarizes the experiences of caregivers and their needs through the concepts of Needs, Motivation, and Helpers/Hindrances and subsequent subconcepts. These elements contribute to the initiation of a Level I theory, kinkeeping for caregivers. An exploration of this inductive theory as well as implications for nursing and recommendations for further research also are presented.

Summary of Findings

The purpose of the qualitative ethnography study was to describe the experience of adult caregivers of elder parents and discover caregiver needs. All caregivers interviewed were middle-class white females, ages 35 to 73 years, who resided with at least one elder parent.

The taped interviews were analyzed using the process described by Field and Morse (1985). Results of content analysis and subsequent verification of findings by informants inspired the researcher to describe the experience of caregiving as a process of kinkeeping. Evaluation of content also revealed two caregiver needs: Quiescence and Emancipation. Although four of five

caregivers received assistance from a formal support system, caregivers hoped for an opportunity for rest from daily duties of caregiving while they protested their confinement. The caregivers required that the essential enterprise for Quiescence and Emancipation be qualified, affordable, and available.

Explanations for the caregivers' commitment to their elder parents emerged as two motivations: Love for Parent and Avoiding Institutionalization. Love for Parent was expressed as a voluntary obligation to "repay" their parents for child rearing as well as an extension of the caregiver's maternal role. The caregivers saw institutions as being places where feelings of love and self-sacrifice were absent. The caregivers were convinced that the parent could never get the same level of care as provided by them.

Those outside the caregiver/elder dyad whose influence was either positive or negative for the caregiving experience consisted of home health and family relations. The four caregivers who accessed formal community services attributed their ability to keep the parent home to the home health agency. As well as personal care for the parent, home health personnel provided the only brief periods of respite available to the caregiver. However, the rest was limited to the

generosity of the personnel rather than as a formal service of the agency.

Finally, quotations pertaining to family more often revealed members as hindrances rather than helpers. Positive statements always included female relations (sister, daughter), whereas the negative statements referred to male members (brothers, husbands, and nephew). The male relative further precipitated caregiver frustration by presuming most caregiving duties would be accomplished by the female. Furthermore, two caregivers upheld their own frustration by reiterating that the role was not "natural" for the male family members.

Discussion

The findings reflecting the experience of caregiving and a discovery of caregiver needs assisted the researcher in identifying three concepts and six subconcepts which contributed to uncovering the model of kinkeeper. This model has consideration as a Level I theory. Level I theory is generally descriptive, naming phenomena and substantiating relationships. Level I theory does not attempt to test associations or predict future trends, rather it proposes to identify variables in order to generate theory (Field & Morse, 1985). Phenomena related to kinkeeping emerged with some substantiation of descriptive relationships; therefore, further discussion of this model as a Level I theory is justified.

The term kinkeeper was established in sociocultural literature by Rosenthal (1985) who defined kinkeeping as an area of family work dominated by females who were depended upon to be responsible for keeping family members in touch with one another. The role of kinkeeper persisted over time, and occupancy was frequently passed from mother to daughter. Having a family kinkeeper was related to greater extended family interaction and greater emphasis on family ritual at both extended family and lineage levels.

The findings of this research suggest kinkeeping as a familial division of labor in caring for elder parents assumed by a single female family member. More than this, the experience of caregiving suggests consideration of kinkeeping as a model with three isolated concepts (Needs, Motivation, and Helpers/Hindrance) and descriptive relationships among the three concepts. In addition, these relationships were interpreted as subconcepts and included Quiescence, Emancipation, Love for Parent, Avoiding Institutionalization, Family, and Formal Support.

For instance, the assumption of the role of primary caregiver by the female not only created frustration but precipitated further exhaustion and confinement, thereby creating the Needs (concept) of Quiescence and Emancipation (subconcepts). Further, the concept of Needs was impacted by the phenomenon of Motivation (concept) by

the caregiver's desire for elder well-being which was directed by Love for Parent and Avoiding Institutionalization (subconcepts). Needs and Motivation also were influenced by Helpers/Hindrances (concept) including Family and Formal Support (subconcepts) so that a change in one concept altered one or both of the other concepts.

The concept of Need which emerged in this research can be validated by findings of previous research while the concepts of Motivation and Helper/Hindrances were not previously mentioned in a review of relevant literature. Thus, the caregiving experience and identified need of caregivers were expanded for consideration as a model entitled Kinkeeping which suggests a Level I theory.

The concepts of Quiescence and Emancipation expressed as needs validated the research of Goldstein et al. (1981) who concluded that confinement of the caregiver in the home and restricted activities were the most severe problems and led to role fatigue. Additionally, George and Gwyther (1986) found that caregivers who resided with the patient experienced low levels of participation in and satisfaction with their social participation. Further, Robinson and Thurnher (1979) concluded that stress resulted when the caregiving relationship was experienced as confining. However, the concepts of Motivation and

Helpers/Hindrances, which were discovered in this study, were not identified in previous studies.

In a professional discipline, research must eventually produce knowledge in the form of theory for the improvement of the practice of that profession. Such knowledge can emerge by describing phenomena and assigning meaning to the findings. The theoretical framework which sustains the profession of nursing also directed this research, the American Nurses' Association definition of nursing. This research employed an ethnographic approach which resulted in the identification of concepts and potential relationships (Field & Morse, 1985).

Further defined by Field and Morse (1985), ethnography is a means of gaining access to the health beliefs and practices of a culture and a subculture, such as caregivers. The researcher is mindful that the sample was limited to white caregivers of middle-class socioeconomic status. Though the findings may be appropriate for this particular subculture, application of the theory of kinkeeping for caregivers requires further research with other socioeconomic classes, cultures, and ethnic groups.

In conclusion, the experience of caregiving of elder parents and the needs of these caregivers were found to be subsumed in the model of kinkeeping for caregivers. Three

concepts were identified and potential relationships among these phenomena emerged.

Implications for Nursing

Nursing can facilitate appropriate interventions only when the phenomena of caregiving are understood. The significance of this study to nursing remains the two basic domains: understanding the experience and the needs of caregivers. For this reason, the research aspired to perpetuate nursing as a profession through theory development.

With an understanding of caregiving through theory development, nursing is offered an explanation of the behaviors of caregivers and patients and provided a base for identifying strengths and weaknesses in nursing practice (Field & Morse, 1985). Ultimately, the goal of the model of kinkeeping is to impact practice through improved understanding of the process of caregiving and to provide the stimulation for continued research of the model to initiate a Level I theory.

In directing the plan of care for a family with dependent elders, it is imperative that nurses consider all caregivers as an at-risk population. Even in ideal environments, the responsibilities of caregiving affect the social, psychological, and physical well-being of the caregiver. Nurses responsible for patients and their caregivers must act as advocate and case manager for the

family. This responsibility implies exploring possible respite, agencies, and reimbursement available within local communities. Furthermore, nurses may initiate policy for establishment of enterprises that may better meet the needs of caregivers.

Recommendations for Further Study

Based on the findings of this study, the following recommendations are made:

1. Further qualitative research studies of adult children of elder parents with a larger and more diverse sample.

2. Further development of the Level I Theory of Kinkeeping for Caregivers of Elder Parents.

3. Implementation of family-as-client intervention in undergraduate nursing curricula.

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APPENDIX A

LEWIS CAREGIVER EXPRESSED NEED INTERVIEW GUIDE

ID #_____
Date:_____

Lewis Caregiver Expressed Need Interview Guide

I. DEMOGRAPHIC DATA (compiled by researcher)

Caregiver age:____ Sex:_____ Occupation:_____

Number of years caring for elder parent(s):_____

Others who help provide care:_____

Age of elder parent(s):_____

Diagnoses:_____

_____

How long has the parent been diagnosed?_____

II. INTERVIEW GUIDE

1. Would you tell me what it has been like to be a caregiver--in the beginning and now?
2. Tell me what a typical day is like in your family group.
3. Would you tell me what you see as your needs as a caregiver?
4. Do you have a way to get these needs met? Please describe.
5. What ways do you see that others might assist you in getting these needs met?

APPENDIX B

LETTER TO PARTICIPANTS

April 20, 1994

Hello. My name is Mandi Lewis. I am a registered nurse from Pascagoula, Mississippi. I am presently a graduate student of Mississippi University for Women pursuing my Master's degree in nursing. I am conducting research that intends to understand the experience and needs of caregivers.

Being the primary caregiver of elder family members can be difficult as well as rewarding. My interest in caregivers began as I observed my family care for its oldest generation.

South Mississippi Home Health Agency has generously allowed me to recruit participants for my study. I am requesting your participation if you are the caregiver of an elder parent who resides in your home and if you have been caring for this person for a minimum of one year.

My study has been reviewed by a special committee, the Committee on Use of Human Subjects in Experimentation, to assure that there is no danger or threat to anyone who participates. Participation is completely confidential and would include an audiotaped interview for approximately one hour, preferably in your home, and certainly at your convenience.

I am urgently seeking to expedite my study. If you think you might be interested, please call me at (601) 769-1268. You are more than welcome to call collect. I have an answering machine if you would please leave a message.

Thank you so very much. May God bless you on this journey in your life.

Mandi B. Lewis, RN

APPENDIX C

APPROVAL OF MISSISSIPPI UNIVERSITY FOR WOMEN COMMITTEE ON USE OF HUMAN SUBJECTS IN EXPERIMENTATION

MISSISSIPPI UNIVERSITY FOR WOMEN
Columbus, MS 39701

Office of the Vice President for Academic Affairs
Eudora Welty Hall
P.O. Box W-1603
(601) 329-7142

March 15, 1994

Ms. Mandi B. Lewis
c/o Graduate Nursing Program
Campus

Dear Ms. Lewis:

I am pleased to inform you that the members of the Committee on Human Subjects in Experimentation have approved your proposed research upon the following condition:

You must obtain permission from the home health agency when dealing in any patient related endeavors.

I wish you much success in your research.

Sincerely,

Thomas C. Richardson
Vice President
for Academic Affairs

TR:wr

cc: Mr. Jim Davidson
Ms. Jeri England
Dr. Nancy Hill
Dr. Rent

APPENDIX D

AGENCY CONSENT FORM

SOUTH MISSISSIPPI HOME HEALTH, INC.

CORPORATE HEADQUARTERS
108 Lundy Lane
P. O. Box 16929
HATTIESBURG, MS 39404-6929
Phone (601) 268-1842

120 North 40th Avenue
P. O. Box 16535
HATTIESBURG, MS 39404-6535
Phone (601) 261-4070

1014 Rogers St.
LAUREL, MS 39440
Phone (601) 649-2231

1010 Main St., Suite 4
COLUMBIA, MS 39429
Phone (601) 736-5131

2037 Old Mobile Highway
P. O. Box 116
PASCAGOULA, MS 39568-0116
Phone (601) 769-1693

106 Willow Creek Drive
P. O. Box 319
LONG BEACH, MS 39560
Phone (601) 864-3239

515 LaFayette Street
P. O. Box 403
LEAKESVILLE, MS 39451
Phone (601) 394-2319

2003 Wildwood Road
P. O. Box 1194
PICAYUNE, MS 39466
Phone (601) 798-1421

703 Station St.
WAYNESBORO, MS 39367
Phone (601) 735-4811

916 Hattiesburg Dr.
P. O. Box 457
MAGEE, MS 39111
Phone (601) 849-4911

1814 Columbia Ave.
P. O. Box 630
PRENTISS, MS 39474
Phone (601) 792-5187

401 Pattiff Street
P. O. Box 21
LUCEDALE, MS 39452
Phone (601) 947-4252

309 Highway 51 North
P. O. Box 3550
BROOKHAVEN, MS 39601-3550
Phone (601) 835-1145

405 Briarwood Drive, Suite 109
JACKSON, MS 39206
Phone (601) 977-0030

112 Lower Woodville Rd.
P. O. Box 17845
NATCHEZ, MS 39120
Phone (601) 442-8311

MARY E. STAINTON
Executive Vice President -
Health Services

April 15, 1994

Mandi B. Lewis, RN, BSN
907 Belair St.
Pascagoula, MS 39567

Dear Ms. Lewis,

Permission is granted to use a sample recruited from South Mississippi Home Health. The staff of the Long Beach and Pascagoula offices have been instructed to identify potential participants regarding the study. Your name and telephone number will be given to the potential participants which will allow them to contact you if they are interested in participating.

To assist the staff with recruiting the participants, it would be helpful if they had some type of a brief handout to give to the potential participants. I would suggest that the information include your criteria and your personal data, i.e. where you are in school, etc. Please be assured that if you decide not to pursue a handout we are still willing to work with you. Let me know your decision regarding a handout.

If Karen or I can be of further assistance, please feel free to call.

Sincerely,

Mary E. Stainton

Mary E. Stainton, M.S., R.N., C.
Executive Vice President
SOUTH MISSISSIPPI HOME HEALTH, INC.

cc: Jill Olsen, R.N. Office Manager, Pascagoula
Sondra Johnson, R.N., Office Manager, Long Beach
Karen Utterback, R.N., Regional Manager
Dr. Mary P. Curtis, Academic Advisor, MUW

WE TAKE THE HOSPITAL TO THE HOME
SMHH
SERVING SOUTH MISSISSIPPI SINCE '69

APPENDIX E

PARTICIPANT AGREEMENT

Participant Agreement

My name is Mandi Lewis. I am a registered nurse and graduate student of the Mississippi University for Women. The purpose of my research is to discover the needs of caregivers who care for elder parents in the home. Few previous researchers have studied caregiver needs in the same manner as this study. I would appreciate your participation by allowing me to come into your home at your convenience and conducting an audiotaped interview.

Your participation in this study is very appreciated. Your signature is required to acknowledge your consent for participation in this study and understanding of the following:

I understand that my participation is voluntary, and at any time in the study up to the time of data analysis I may be excluded from the study.

I understand that the interview will be tape-recorded for the purpose of data analysis and that my identity will remain confidential.

I agree to the researcher's sharing the interview information in both written and verbal form with her professional colleagues for the purpose of student learning and for the development of nursing knowledge.

Signature:_____ Date:_____

Researcher:_____ Date:_____